

Investigation Report On the Death of Ricky W.



State of Connecticut
Fatality Review Board for Persons with Disabilities

March 2005

In an effort to bring more independent oversight to the process of reviewing and investigating the deaths of individuals who receive services from the Connecticut Department of Mental Retardation, Executive Order #25 was promulgated on February 8, 2002. The Executive Order requires the Department of Mental Retardation (DMR) to report all deaths of persons placed or treated under the direction of the Commissioner of Mental Retardation to the Office of Protection and Advocacy for Persons with Disabilities (OPA). It also establishes the Fatality Review Board for Persons with Disabilities. Comprised of law enforcement, medical and mental retardation professionals, the Fatality Review Board is chaired by OPA's Executive Director. The Board is charged with investigating the circumstances surrounding those untimely deaths of DMR clients which, in the opinion of the Executive Director, warrant full, independent investigation.

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Office of Protection and Advocacy for Persons with Disabilities*

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Hospital of Saint Raphael*

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UCP of Eastern Connecticut, Inc.*

*Timothy M. Palmbach, Director
Forensic Science Program
University of New Haven*

*Kirsten Bechtel, M.D.
Pediatrician
Yale New Haven Hospital*

*John L. DeMattia, Esq.
Supervisory Assistant State's Attorney
Director Medicaid Fraud Control Unit*

DEPARTMENT OF MENTAL RETARDATION LIAISON

*Mr. David Carlow, R.N.
Director of Health and Clinical Services*

STAFF

*Anne Broadhurst, MSW, Project Manager
Barbara L. Roy, Executive Secretary*

CONSULTANTS

*Michael M. Baden, M.D.
Saadia R. Akhtar, M.D.*

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INVESTIGATION BACKGROUND

On April 5, 2003, late evening news broadcasts across Connecticut carried a profoundly disturbing story: a 39 year old Hartford man with mental retardation had died following a vicious assault in the lobby of his south end apartment building. The man was identified as Ricky W.

In the days that followed, additional details were reported: The police investigation had resulted in the arrests of a total of five juveniles ranging in age from 12 to 14. The assault had been captured on a surveillance videotape that depicted several of the youths throwing large, plastic soda bottles at Ricky. One of the bottles struck his head, knocking him to the ground. The tape showed that while he lay on the ground, motionless, his pants were pulled down, soda was poured over him, and he was kicked repeatedly.

Additional facts about Ricky's life also began to emerge: He had been known to his neighbors as "Batman" because he would sometimes dress up in a homemade Batman costume and patrol outside his apartment building. He had lived at Southbury Training School for over ten years, moving in 1995 to a supported apartment program (officially called a Supported Living Arrangement, or SLA) in Manchester. While he had mastered the housekeeping skills he needed to take care of himself and his apartment, his neighbors were sometimes intimidated by his size, or put off by his neediness for personal attention and his lack of social judgment. In fact, Ricky had been asked to leave his previous apartment in Manchester largely because of difficulties with neighbors. Throughout his adult life he had had to struggle with the effects of mental illness as well as his intellectual disability.

Despite the challenges he faced, however, newspaper accounts accurately reported that Ricky W. was a man steadfastly determined to live an independent life in the community. In fact, he had become a respected and popular member of the self-advocacy movement for people with mental retardation, and was an articulate spokesperson for the right of people with mental disabilities to live as full members of their communities. At public meetings Ricky could be counted on to ask perceptive questions of candidates for public office and appointed officials concerning their views on community services. He had received recognition for his advocacy skills, including an award from the statewide advocacy organization, ARC-CT.

Several articles quoted relatives and friends who questioned whether the south end neighborhood where Ricky had been living was an appropriate location for someone with Ricky's disabilities. Others dismissed these concerns, pointing out that Ricky had chosen to move to Hartford, and that other DMR clients had lived in the same area without incident. However, the fact that Ricky had died while being taunted and

assaulted by neighborhood youth had a profoundly unsettling effect on people living in similar “supported living” programs. Many advocates and service providers viewed his death as a hate crime. Old wounds from schoolyard bullying were revisited and worries about personal safety were aired at self-advocacy meetings. People were shaken and felt vulnerable. How safe was anyone in a world where something like this could happen to a big, gregarious and determined friend like Ricky? A coalition of advocacy groups began to pursue legislation explicitly criminalizing hate crimes against persons with disabilities. They dedicated their efforts to Ricky’s memory.

And then, in June, 2003, there was some surprising news. An autopsy conducted by the Office of the Chief Medical Examiner had determined that the manner of Ricky’s death was “natural”; that his death was caused by complications associated with an enlarged heart, not from traumatic injuries incurred during the assault. The medical examiner’s office determined that Ricky had experienced “sudden death due to idiopathic cardiomegaly”, listing diabetes as a contributing factor. (Suspected diabetes had been reported by the ambulance crew that had brought Ricky to the hospital following the assault. Newspaper articles repeated this information. When it was later determined that Ricky had never had diabetes, the official autopsy report was amended to delete reference to diabetes.) Because the medical examiner’s office determined the manner of death to have been “natural”, as opposed to “homicide”, charges against the assailants were limited to criminal attempt to commit assault in the first degree on a mentally retarded person, and conspiracy to commit such an assault. Four of the five juveniles accepted plea arrangements involving sentences of incarceration. (As of this writing, a fifth youth still faces trial on these charges.)

Against this background, the Fatality Review Board for Persons with Disabilities (FRB), supported by staff from the Office of Protection and Advocacy for Persons with Disabilities (OPA), commenced an investigation into the circumstances surrounding Ricky’s death. Consistent with its charge to conduct full, independent investigations, the FRB identified three discrete goals for the inquiry: 1) to examine the events leading up to and surrounding Ricky’s death; 2) to identify any relevant issues and concerns regarding Ricky’s supports and care; and 3) to determine whether any lessons could be learned to help improve community responses and service systems for people who are similarly supported in the community.

INVESTIGATION PROCESS

During the course of this investigation, FRB staff conducted extensive interviews with people who had known or worked with Ricky W., including staff from Southbury Training School, staff and managers employed by the Supported Living Arrangement program provider that served him in the community, DMR case managers and contract managers, advocates, physicians, nurses, apartment complex

property management, friends and family members. All available medical and DMR service records dating from 1984 were reviewed, as were autopsy reports, police investigation reports and arrest warrant affidavits. Hartford Police investigators and staff from the Office of the Chief Medical Examiner were also interviewed, and clarifications regarding charges brought against the assailants were provided by the Hartford State's Attorney's office. The Forensic Services Division of the Connecticut State Police provided videotape enhancement technology to afford FRB members and staff with an opportunity to review a surveillance videotape recorded from a camera in the apartment house lobby in which Ricky was assaulted. To ensure thorough, independent review of medical records and autopsy results, the FRB engaged the services of an independent forensic pathologist, Dr. Michael Baden, and a consulting pulmonologist, Dr. Saadia R. Akhtar.

Having completed its investigation, the FRB makes the following findings and recommendations:

FATALITY REVIEW BOARD FINDINGS

1. There is considerable evidence that the harassment and assault by the five juvenile assailants, as recorded on the surveillance videotape in the lobby of his apartment building, precipitated Ricky's death. This finding stands in contrast to the official findings of the Connecticut Office of the Chief Medical Examiner (OCME), which determined the manner of Ricky's death to be "natural".

- During a December 2003, meeting with FRB members and investigation staff, Assistant Medical Examiner Malka Shah, who had conducted the autopsy, expressed the belief that, based on her examination and her review of the surveillance tape, Ricky had probably died before the physical assault had begun, while he was half-seated, half-leaning against a radiator cover mounted on the wall in the lobby of his apartment building. Dr. Shah concluded that a soda bottle thrown by one of the assailants struck Ricky's head with sufficient force to cause his body to fall over onto the floor. This conclusion was based partly on the observation that Ricky did not appear to move after he had been knocked to the floor, and partly on the absence of post mortem evidence of significant trauma. (The autopsy found no evidence of bruising or major injury to the head or internal organs. Although the post mortem examination did not reveal any signs of bruising, OCME staff acknowledged that, due to the darkness of Ricky's skin, evidence of more superficial bruising in the area of his head might not have been easily observed, absent dissection of layers of skin – a procedure that was not performed out of consideration for the family.) Given the underlying cardiac condition demonstrated on autopsy (which

the OCME diagnosed as “idiopathic cardiomegaly”), and the fact that there were no definitive post mortem tests that could determine what effect the stress of the confrontation may have had, Dr. Shah concluded that the manner of Ricky’s death had been “natural”.

- FRB members note, however, that the surveillance tape shows Ricky moving about somewhat before the bottles were thrown at him. At various points during the five-minute period prior to commencement of the assault, he is seen attempting to gather a carton and several bags of large plastic soda bottles he had just carried into the building from a local convenience store. Following each such effort, he is seen to sag back against the wall, propping himself against the radiator cover, sometimes lowering his head as if extremely fatigued. While he is motionless between these spurts of exertion, and appears unwell, the tape clearly shows him raising his right hand just prior to his falling to the floor, as if attempting to ward off the soda bottle that struck his head, or possibly to keep his balance.
- Statements taken from the assailants by Hartford police officers also suggest that Ricky was in considerable physical distress, but still alive at the time the assault commenced. The assailants describe Ricky at various times as shaking and drooling all over himself, stumbling around the lobby attempting to pick up soda bottles, drinking a soda and dropping it, looking like he was sleeping while he was standing up, leaning against the wall, and appearing to be breathing. The assailants report that once Ricky fell to the floor, he didn’t seem to be breathing. While the images from the video are decidedly grainy, they tend to confirm these observations.
- The FRB asked Dr. Michael Baden, a well known independent forensic pathologist based in New York, to review the results of the post mortem exam and the surveillance tape. In Dr. Baden’s opinion it is clear that Ricky had an undiagnosed and untreated medical condition that compromised his ability to breathe (“Pickwickian Syndrome”, or more properly, “obesity-hypoventilation syndrome”). Dr. Baden interpreted the videotape evidence as indicating that Ricky was exhibiting signs of significant physical distress at the time the assault occurred. His report states that Ricky’s behavior, as depicted on the surveillance videotape, “shows evidence of diminished oxygen saturation in the blood, which caused Ricky to appear slow and lethargic.” It is documented that Ricky had experienced previous episodes of similar distress in the past, for which he had been brought to emergency departments on several occasions, and even hospitalized. Noting both the post mortem and videotape evidence of Ricky’s compromised health status, Dr. Baden concluded that the added stress of the assailants’ taunts and bottle throwing “likely triggered off a

fatal cardiac arrhythmia” in this instance and “shortened Ricky’s life.” According to Dr. Baden, “the manner of death would then properly be homicide.”

2. There is substantial evidence to suggest that Ricky’s health care needs were not properly understood or adequately provided for by those responsible for supporting him in the community.

- Ricky stood 5 feet 9 inches tall. When he left Southbury Training School (STS) in 1995, he weighed approximately 260 pounds. His STS physician recommended that due to Ricky’s weight and medication regime, he should have regularly scheduled electrocardiograms, as well as periodic blood counts, liver enzyme and cholesterol screenings, and urinalysis and routine blood work to monitor for diabetes. However, despite statutory requirements that DMR clients receive “prompt, sufficient and appropriate medical and dental treatment”, there is no evidence that these specific recommendations were communicated to community-based health care providers, or that a comparably comprehensive plan for monitoring Ricky’s health status was independently developed by his community-based providers. (Connecticut General Statute 17a – 238(e) mandates that “the Commissioner of the Department of Mental Retardation shall ensure that each person placed or treated under the commissioner’s direction in any public or private facility is afforded the right to prompt, sufficient and appropriate medical and dental treatment”).
- Ricky continued to gain weight while a client in the Supported Living Arrangement program, weighing approximately 330 pounds at the time of his death. Although he received a great deal of counseling and advice on the need to eat a healthy diet and exercise regularly, and he often chose to do otherwise, this weight gain represented an increasing health risk factor. In addition, he began to present signs and symptoms of potentially serious medical problems such as shortness of breath; lethargy; occasional episodes of slurred speech; occasional loss of consciousness; frequent, unexplained nausea and vomiting; and systemic hypertension with narrowed pulse pressure differential. In addition, several laboratory studies conducted concurrent with hospital visits showed blood gasses (e.g. oxygen saturation) and ph values well outside of normal limits. A chest x-ray taken during one hospitalization demonstrated “cardiomegaly with possible vascular findings”. However, despite these signs, symptoms, test results and the ongoing presence of obvious risk factors, little attention seems to have been paid to coordinating his health care services.

Specifically:

- Ricky's primary care physician continued to see him primarily for annual physicals and at irregular intervals when Ricky requested treatment. Although Ricky told him about his symptoms, and the doctor had signed off on hospital discharge summaries that included laboratory and radiology reports with significant findings, he ordered few follow-up tests and no specialty consultations. When interviewed, he indicated that he thought "the State" had ensured that Ricky was well cared for.

- The private Supported Living Arrangement provider agency that DMR contracted with to serve Ricky had no medically trained staff members. That agency had found the primary care physician for Ricky, but saw its role in Ricky's health care primarily in terms of transporting him to appointments and arranging for weekly nursing visits from home health agencies. (Two home health agencies were involved at different points in time.)

- Charged with assessing Ricky's condition, monitoring vital signs and providing health-related education, nurses from these home health care agencies documented that they did provide information about Ricky's health status to both the primary care physician and Ricky's psychiatrists. However, there are many gaps, unanswered questions and indications of miscommunications suggested in the records made by these nurses (e.g. periodic unexplained absence of blood pressure readings, conflicting information about medication dosages, and questions about the validity of blood pressure values that may have been measured with different size blood pressure cuffs – a significant issue for an individual as large as Ricky). In addition, despite obvious concerns with Ricky's weight, there was no scale available to weigh him. Perhaps most significantly, nurses from the home health agency did not attend interdisciplinary team meetings where they could have made case management and support staff aware of the significance of Ricky's increasing health risks, the importance of monitoring his status, and where they could have contributed to service planning processes.

- When the second home nursing agency discontinued services to Ricky three months prior to his death, no one made arrangements for a replacement. Instead, the Supported Living Arrangement program provider arranged to get weekly supplies of pre-packaged medications through a local pharmacy. Although the primary care physician indicated that some kind of replacement for the home health agency was needed, his records also reveal a belief that this need could be

addressed through “case management”. No doubt this reflected a sincere belief on his part, but it did not comport to the reality of Ricky’s service system.

- As with the Supported Living Arrangement provider, no one on the DMR Interdisciplinary Team that was responsible for identifying Ricky’s needs and monitoring his services, including his case manager, had sufficient training or professional health care background to recognize the vital importance of close monitoring, communication and persistent follow-up with his doctors. There was a presumption that because Ricky was his own guardian, he was capable of, and ultimately responsible for, navigating the health care service system on his own. In fact, given the multitude of health problems and risk factors Ricky presented, the most notable feature of his support system was the absence of a qualified, unambiguous fixed point of responsibility for coordinating his health care.
- Beginning in 1997, Ricky complained of frequent nausea and vomiting. One such episode prompted a call to his primary care physician, who noted that an office visit should be scheduled for purposes of a “GI work up”. However, the FRB investigation found no evidence in Ricky’s medical records that the office visit was ever scheduled, or that a comprehensive gastrointestinal work up (e.g. full history and follow-up diagnostic studies) ever occurred. Nor is there any indication that a potential link was considered between Ricky’s persistent nausea and the evidence of impaired respiratory function that had emerged following episodes of disorientation, shortness of breath, and unconsciousness that had resulted in his being brought to hospitals in 1998.
- In March, 1998 Ricky was hospitalized following an episode where he lost consciousness. This hospital admission followed several emergency room visits and witnessed episodes of shortness of breath, slurred speech, drooling, and increased lethargy. Laboratory studies performed prior to hospitalization revealed that Ricky’s oxygen saturation levels were considerably below normal values and that his carbon dioxide levels were significantly elevated. (Ricky’s oxygen level measured 25. Conventional values range from 75 to 100. His carbon dioxide level measured 56, whereas conventional values range from 35 to 45.) A chest x-ray performed at the same time revealed “cardiomegaly (enlarged heart) with question of increased vascular findings”. Ultimately, Ricky was diagnosed with Sleep Apnea Syndrome, and discharged with orders for a BiPAP device to afford ventilatory support and supplemental oxygen during sleep. It was recommended that he consult with a pulmonologist for further evaluation of this condition. However, there is no evidence that this

recommendation was ever pursued, or that subsequent to this hospitalization, his primary care physician followed up by ordering blood gas levels or other related laboratory studies. Nor was he referred for further work up of the enlarged heart that had been noted on the chest x-ray, despite the fact that he was again brought to a hospital emergency room several months later with similar symptoms.

- Lack of follow up on these issues contributed to the persistence of Ricky's symptoms of illness, his chronic lethargy and, quite possibly, shortened his life. In addition to reviews by its own physician members and the consulting pathologist, Dr. Baden, the FRB requested that an independent pulmonologist, Dr. Saadia R. Akhtar, consult with the Board and review records of Ricky's medical treatment. Noting that the post mortem exam revealed that the right-side of Ricky's heart was enlarged – a condition termed “cor pulmonalae” -, both Dr. Akhtar and Dr. Baden expressed the opinion that Ricky's respiratory difficulties likely involved more than “sleep apnea”. Interpreting the autopsy findings in light of Ricky's episodes of daytime lethargy, slurred speech, and history of abnormal blood gas studies, both specialists concluded that Ricky had suffered from a condition known as “obesity-hypoventilation syndrome” (OHS) – sometimes referred to as “Pickwickian Syndrome” (so named after one of the characters in Charles Dickens' “Pickwick Papers”). Due to their obesity, individuals with this condition cannot expand their lungs sufficiently to ensure an adequate exchange of oxygen and carbon dioxide, even during waking hours. According to the Dr. Akhtar, “If untreated, persons with OHS will develop pulmonary hypertension and cor pulmonale (right side heart failure, manifest as shortness of breath, weight gain, peripheral edema and, ultimately, arrhythmias or complete heart failure and collapse).” She concluded that Ricky was “quite ill” and that based on her review of the autopsy report and medical records obtained by the FRB, he suffered from “...systemic hypertension and severe obesity hypoventilation syndrome with probable obstructive sleep apnea, pulmonary hypertension and cor pulmonale. It does not appear that he received the usual recommended care for these conditions.” Dr. Baden concurred. Although he clearly states that Ricky “would not have died when he did if [the juvenile assailants] hadn't struck and taunted him”, he also expressed the opinion that Ricky might not have succumbed during the assault, “if the underlying medical condition that caused his symptoms from decrease in oxygen saturation was properly diagnosed and treated.”
- Ricky's records reveal persistent discrepancies between medication dosages ordered and those administered, as well as lack of consistent monitoring of blood levels of prescribed medications, particularly Lithium.

They also demonstrate a lack of attention to cardiovascular monitoring prior to and during the introduction of a new psychotropic medication, Geodon, for treatment of his bipolar disorder. According to information provided by the drug's manufacturer, Geodon can increase a person's chance of experiencing cardiac arrhythmia (abnormal heart rhythm) if the person has certain cardiac conditions or takes certain other medications. The drug manufacturer advises that because of this possible risk, Geodon should only be used after one's physician has considered this risk against the risks and benefits of other medications. Individuals considering this medication are also advised that they should inform their health care provider if they have any history of heart-related illness or disease, or any family history of heart disease or heart problems. As previously stated, tests performed during Ricky's hospitalization in 1998 revealed that he had cardiomegaly, or an enlarged heart, with "questionable vascular findings." However, there is no evidence in Ricky's records to suggest that either his primary care physician or psychiatrist obtained a family medical history or performed any tests prior to initiating the Geodon. In fact, there is no evidence that they even consulted with each other concerning the risks and benefits of using Geodon prior to its introduction.

- Although DMR's "Follow Along Plan" called for Ricky to be seen by his psychiatrist once every three months, or more often as needed, Ricky's records reveal that this did not occur. (A Follow Along Plan is a document prepared annually for individuals receiving services in a DMR Supported Living Arrangement.) Part of the problem involved finding and keeping a psychiatrist to treat him. Between 1995 and his death in 2002, Ricky was a patient of four different psychiatrists. FRB investigators were unable to learn why the first of these psychiatrists stopped seeing Ricky; the second appears to have been unwilling to complete the paperwork necessary to satisfy DMR's policy for reviewing behavior-modifying medications; the third left private practice; and, the fourth had just begun consulting with Ricky when he died. The end results, however, were somewhat inconsistent diagnoses and inconsistent intervals between visits. On at least one occasion as many as eight months elapsed between psychiatric visits. There is also no evidence that regular monitoring of his prescribed medication saturation levels occurred during this timeframe.

3. There is considerable evidence that the mental retardation service system misunderstood Ricky's needs and capabilities and did not adequately respond to his changing needs.

- People who knew Ricky respected his ability to advocate for himself and his determination to live on his own in the community. Although he took

legitimate pride in his achievements and developed many positive relationships with community members, he was also very needy for personal attention, tended to misread social cues, and was perpetually short on cash. He frequently asked neighbors for food, and sometimes became involved in less than cordial verbal exchanges when they refused. These behaviors bothered his neighbors beyond the point where they could ignore or tolerate them. On several occasions neighbors called police to complain about Ricky's behaviors (although formal charges were not pursued). More often they complained to building managers. Between 1995 and the time of his death, Ricky was asked to leave, or was actually evicted from six apartments and was undergoing eviction proceedings from his last residence when he died. While Ricky received counseling episodically and a behaviorist was consulted to develop a program to address the behaviors that were getting him into trouble, neither approach produced lasting improvement.

- After Ricky moved for the fifth time, the Supported Living Arrangement (SLA) provider and Ricky's DMR Interdisciplinary Team recognized that the supported living program operated by the provider was inadequate to meet his needs. In July 2001, the SLA provider notified DMR by letter that it would discontinue services to Ricky in 30 days. The letter stated that Ricky "truly requires a high level of support and structure". In anticipation of being relieved of responsibility for supporting him, the provider began to lay off staff and halved the number of hours of weekly support it had provided to Ricky. Although some efforts were undertaken by DMR to secure another provider and different type of living arrangement for Ricky, a suitable alternative provider was not found. In March 2002, the provider ultimately accepted continued responsibility for serving Ricky, and gradually restored support hours to him. At an Interdisciplinary Team meeting attended by his DMR case manager, advocate, and supported living program staff, the provider agreed to continue to provide services to Ricky as long as he accepted certain behavioral conditions. Ricky agreed.
- By that time, however, the service system had become used to operating with a narrow focus on forestalling or recovering from Ricky's frequent evictions. Rather than building on long-range aspirations and developing strategies to support his personal growth and positive contributions to community, IDTeam members and SLA program staff concentrated their efforts on solving immediate problems and attending to chronic concerns such as difficulties with landlords, budgeting issues, and the increasingly difficult task of locating alternative housing. For the most part, they saw these chronic problems as a function of Ricky's behaviors and bad habits.

As a matter of routine, staff would remind him about the need to pursue healthy dietary habits and to avoid behaviors that annoyed neighbors. They would sometimes walk with Ricky around his neighborhood as a means of assuring he got some exercise. While some program staff maintained consistent, generally positive relationships with Ricky, interviews with staff and notes from meetings suggest that those working with Ricky were not operating with the kind of long-range, positive vision of the future that could help him (and them) move on to a better place.

- Ricky's relative poverty also limited his housing options and contributed to difficulty focusing on "big picture" goals. Unlike many individuals served through Supported Living Arrangements, Ricky did not work, and, in fact, seemed uninterested in securing regular employment. This meant he had to live on a minimal income from entitlements which, in turn, limited opportunities to pursue interests and achieve material goals. In retrospect, it seems likely that his unrecognized ill health probably contributed to his overall lethargy and disinterest in work. But it is also true that Ricky had little personal experience upon which to build a sense of the value of work, or a positive identity as a worker. While they did arrange several part-time and volunteer jobs – jobs which lasted for several months - , and would periodically encouraged him to apply for part-time employment, those supporting Ricky saw his disinterest in working as a choice, and his resulting tight budget as a natural consequence of his unemployment. They hoped he would come to realize this as well. However, given his lack of grounding in work situations, his labile emotions, neediness for relationships, and the particular mix of social skills and deficits he manifested, he might have benefited from, and surely would have needed, a more sophisticated strategy for vocational training and support.
- Following Ricky's death, concerns were voiced by some about the propriety of locating an apartment for Ricky in a large building in a moderate income urban neighborhood. However, having interviewed police investigators, building managers and DMR staff, the FRB found insufficient evidence to support this concern. While Ricky would sometimes talk of moving to different towns, he and an independent advocate had been involved in the search for his latest apartment and in the decision to move to Hartford. Although his income level and history of past evictions left him with relatively few options, at various times prior to his death, he did express satisfaction with the location, and, in discussions with friends, took evident pride in the fact he was living there. Building managers and police indicated that over a period of several years, significant, largely successful efforts had been made to ensure the security

of building residents, and that the neighborhood was not perceived as especially dangerous.

- There were a number of people with whom Ricky interacted on a fairly regular basis. Some of these individuals, such as his mother, visiting nurses, psychiatrist, friends from church, and the superintendent of his apartment building had insights and highly relevant information about Ricky's history and what was going on in his life. Yet no means existed for tapping into the information or observations these individuals could have contributed to monitoring his well being or adjusting his supports. As a result, SLA program staff was completely unaware of some worrisome trends: According to the building superintendent, since moving to Hartford in September 2002, Ricky had begun donning a homemade Batman costume during early morning hours and was appearing outside his apartment building in an attempt to ward off perceived drug dealers. (The costume had originally been assembled for a Halloween party.) The superintendent also reported that Ricky would cry sometimes and say that he was lonely. And, according to a friend who Ricky had met through the church he had begun to attend, he also had also been troubled by some problematic encounters with neighboring youth – troubles the friend had offered to help with, but that Ricky insisted he could cope with on his own.

FATALITY REVIEW BOARD RECOMMENDATIONS

Based on its findings, the FRB makes the following recommendations:

- 1. The Connecticut Office of the Chief Medical Examiner (OCME) should review the results of its post mortem examination and findings, which determined the final manner of Ricky's death to be "natural". Attention should be specifically focused on reviewing the surveillance video tape and the reasons offered by Dr. Michael Baden to support his opinion that the stress of the assault "likely triggered off a fatal cardiac arrhythmia" which "shortened Ricky's life [and that] the manner of death would then properly be homicide."**
- 2. All criminal case files related to this matter should be reviewed by the Hartford State's Attorney to determine whether, given the findings of this investigation, there is sufficient evidence to suggest additional criminal liability.**
- 3. DMR should review the health status of all clients living in Supported Living Arrangement programs (SLAs) to identify those who face significant health problems or risk factors and who also have no clearly identified source of**

knowledgeable health care advocacy to assist them in navigating health care systems and assuring their health care needs are met.

- The Supported Living Arrangement program model is well suited to meet the daily support needs of many individuals with mental retardation. The success of this program owes much to its flexible nature – the ability to tailor the amount and type of staff support and other features according to individual needs. However, unlike more traditionally supervised residential program models (e.g. group homes); there are fewer requirements for multi-disciplinary planning and oversight of issues such as client healthcare. This aspect of the Supported Living Arrangement program design should be reviewed. The mental retardation service system's responsibility to ensure that its clients receive prompt, sufficient and appropriate medical care does not diminish simply because it serves an individual through a Supported Living Arrangement rather than through a more traditional model.
- Specifically, more attention needs to be paid to assuring that SLA clients who have significant health problems or who present significant risk factors are identified and well supported in their efforts to secure appropriate healthcare. Because individual SLA clients may or may not have the capacity to pursue appropriate health care on their own, and to make their own health care decisions without appointment of a guardian, determining the extent of SLA clients' needs for support in this area should be done on a individual, case-by-case basis, with due consideration given to the individual's risk factors, health status, personal resources and the effectiveness of other, existing sources of support and healthcare advocacy.
- The fact that an individual does not meet the criteria for appointment of a medical guardian does not automatically signal an ability to navigate successfully in contemporary healthcare environments. A person with mental retardation may be quite capable of making his or her own decisions with respect to healthcare, yet, like many non-disabled persons, experience difficulty negotiating a healthcare world characterized by variable quality and ever-increasing complexity and fragmentation. (See Sections 45a-669 (f) and (g) of the Connecticut General Statutes, which define the statutory standards for probate court decisions on guardianship of mentally retarded persons). It cannot be assumed that individual DMR clients – whether they are considered to be their own guardians, or have court appointed guardians - will be able to secure quality health care without well informed assistance.
- While the FRB recommends screening all SLA clients to identify those with significant health risk factors, it also recognizes that some SLA clients who have significant health issues benefit from considerable involvement by family

members, guardians or others who are actively involved in assisting to secure the individual's healthcare, and who have also clearly demonstrated a sophisticated ability to navigate health care systems. This is particularly true where an individual client's healthcare is, and has historically been seen to through his or her family's network of physicians and other providers, and family members are involved in assuring that the individual receives adequate care. This recommendation recognizes that DMR may meet its responsibility to assure that client needs are met by identifying and respecting such "natural supports" where they exist.

4. **For those SLA clients identified as having health-compromising conditions or significant health risk factors and who have no existing, knowledgeable health care advocacy source, DMR should ensure that a qualified health care professional is available to assist the individual and his or her support system in understanding and managing health care needs. This health care professional (ideally a Registered Nurse) would be able to advise the individual client (and any guardian, family members or friends the client identifies), participate in interdisciplinary team processes, and educate provider staff and other team members about the implications of the individual's risk factors and chronic health problems. The designated health care professional would also be positioned to vigorously follow-up with physicians and other health care providers to ensure the quality and continuity of the individual client's health care, and to call for second opinions or changes in providers where warranted.**
- In contrast to requirements for operation of Community Living Arrangements (group homes) and other traditional residential support models, there is no requirement that nursing staff contribute to individual assessment, monitoring or service planning for individuals served through SLA programs. Some SLA providers do employ nurse consultants; others, such as Ricky's provider, do not. While home health care agencies are often requested to monitor the health status of SLA clients, home health agency nurses prepare reports for a physician, not a DMR team. In addition, home health agencies serving SLA clients receive payment through Medicaid, not DMR. These agencies do not usually permit their staff to attend DMR service planning and coordination meetings, as Medicaid does not reimburse them for time spent at such meetings.
- A number of approaches could be taken to implementing this recommendation: DMR could directly assign its own staff nurses to follow SLA clients with significant health problems/risk factors; SLA providers could be required to employ nurse consultants who would assume "patient advocacy" as well as planning and education responsibilities; or, DMR could

provide supplemental reimbursement to home health care agencies for allowing nurses employed by those agencies to participate in individual client planning and quality assurance processes. The most critical factors would be ensuring continuous involvement by nursing personnel that know the individual client, and clearly defining the nurse's role as one that ensures that the client receives high quality health care.

5. DMR Case Managers and private agency case managers or social workers who lead interdisciplinary teams that do not normally include a nurse, should receive formal training concerning when and how to involve DMR Regional Health Services Coordinators on behalf of individuals whose health status seems to be deteriorating, or who receive multiple medical services that may require comprehensive health services coordination.

- When Ricky first entered the SLA program, he did not manifest symptoms of significant illness. Although his weight and medication regime suggested that he was at risk of developing chronic health problems, he did not begin to complain about feeling ill until he had been living in the community for 18 months. In fact, the first clear evidence of that he had developed major health issues emerged during a hospital stay in 1998 – three years after he had initially become a client of the SLA program. As with Ricky, it is possible that SLA program clients who currently enjoy good health will experience episodes of significant illness or deteriorating health. DMR case managers and provider staff who oversee SLA client services should be trained to recognize indicators of increased need for health services coordination, and should know when and how to involve DMR's regional health services coordinators on behalf of clients whose health status appears to be deteriorating.

6. Consistent with the need to preserve both clients' rights to confidentiality and the integrity of relationships with their clients, providers of supported living services should develop respectful ways to monitor the contexts in which their clients live, and, with the agreement and consent of the client, respectfully seek input from important individuals in the person's life.

- Partly to maintain trusting relationships with clients who are wary of efforts to control their lives, partly out of respect for privacy rights, and partly to avoid stirring resistance and interfering with potentially positive, naturally occurring community relationships, SLA programs generally try to keep a low profile in the neighborhoods where their clients live. While this strategy works well in many cases, it also creates a risk that important needs or vulnerabilities will go unrecognized. SLA programs need to strike a reasonable balance between delivering unobtrusive, mutually agreed upon supports on the one hand, and

safeguarding against unreported trouble on the other. Doing so need not mean running roughshod over client rights or relationships. Nor would it require expanding reliance on formal, multidisciplinary assessment and planning processes. However, it does mean thinking beyond traditional paradigms, and working to ensure that the client understands that subtly and quietly obtaining feedback from others reflects a genuine commitment to his or her success.

CONCLUSION

Ricky W's life stands as an inspiration to those who knew him and to anyone else who takes the time to hear his story. How he struggled, what he overcame, who he touched along the way, and above all his indomitable yearning for freedom and belonging, speak to all of us in a universal language that transcends diagnostic labels and human service jargon. Like thousands of other Connecticut citizens with disabilities, Ricky embraced life as a full member of the human community. It is clearly right that those who served him respected his wishes and tried to support his choices. Without DMR's Supported Living Arrangement program, it is doubtful that Ricky could have achieved as much as he did, or that others with intellectual disabilities would have the opportunities they now enjoy to live in and contribute to our communities. To honor his life, however, requires that we learn from our experiences serving him. And, there is much to learn. As it issues this report, the Fatality Review Board for Persons with Disabilities hopes that its findings and recommendations will lead to improvements and positive changes that will benefit other individuals who need and receive support services as they make their lives in communities throughout Connecticut.